

Autism Insurance Parity Proposal

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Autism and autism spectrum disorders (ASD) are complex biomedical brain disorders¹. The severity of these disorders varies along a continuum, with some individuals having more profound problems in one key diagnostic area than others, and is associated with the full range of cognitive abilities. As is true of many other biomedical disorders, there is currently no cure for autism. Rather, autism care is focused on controlling or diminishing symptoms and associated impairments. In this way it does not differ from numerous other chronic medical disorders whose treatment is covered routinely by health insurance, including hypertension, diabetes, renal failure, and asthma.

Additionally, there is evidence that a number of diverse treatments can lead to improved functioning in autism, some to remarkable degrees. Like many other medical conditions these treatments include non-pharmacologic approaches. For instance, exercise, general diet and avoidance of environmental factors such as salt and concentrated sugars are considered to be key elements of the management of hypertension and diabetes. Very often these treatments lead to markedly improved function.

(a) Social Impact:

Multiple strands of the submitted evidence to the “The Caring for Washington Individuals with Autism Task Force (ATF)” support the fact that ASD related services are needed by significant numbers of Washingtonian children. In their executive report to the governor at the end of 2007, the ATF named health insurance coverage of autism related treatments for individuals as the number one priority for the state of Washington. This was after two years of carefully studying available resources and the needs of the state. For a complete review of the report, please go to the following link (see pg. 17 of 139):

http://www.doh.wa.gov/cfh/mch/Autism/documents/2007_Report/ATFRptFinal1207.pdf

(i) To what extent is the benefit generally utilized by a significant portion of the population?

Because ASDs are chronic, often disabling disorders, by definition *all* children who meet the diagnostic criteria for ASDs have important health and related needs. Recent evidence from multiple epidemiologic studies, including two of those submitted^(2,3),

1 This is a clearly established fact that is also stated in several of the pieces of evidence such as the autism fact sheet from the National Institute for Child Health and Human Development which states “Autism is a complex neurobiological disorder”.

2 Frombonne E, 2005. Epidemiology of autistic disorder and other pervasive developmental disorders. Journal of Clinical Psychiatry 66(suppl 10):3-8.

3 CDC Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007. Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network Surveillance, 14 sites, United States, 2002. Morbidity and Mortality Weekly Report 56/SS-1:12-28

points to a population prevalence of ASDs of about 1 per 150 children. There is no reason to believe that the true prevalence of ASDs among children in WA is lower from that estimated in the recent studies. It is clear that a substantial number of Washingtonian children have ASD according to Office of Superintendent of Public Instruction (OSPI) 6,025 children with ASD were served in Washington schools in 2007, a 15% increase from 2006. This does not include children who are pre-school age or younger, home schooled or in private schools.

(ii) To what extent is the benefit already generally available?

Although the submitted evidence in the Caring for Washingtonians with Autism Task Force documents that many comprehensive services for children with ASD exist in WA (such as comprehensive developmental assessment, combination of behavioral, physical, occupational, and speech therapies, and in some cases, medications and other related medically necessary treatments), it also identifies important barriers that reduce access to those services.

Personal experiences described by parents and other family members, as well as the independent status report by the Washington State Autism Task Force in 2007 clearly shows that medically necessary treatments for individuals with Autism are not widely available through any state agencies and are routinely denied by insurance based on several misconceptions:

- Autism is widely regarded erroneously as a mental illness, which often leads to referrals to inappropriate and ineffective treatments such as counseling or psychotherapy instead of neurodevelopmental, cognitive behavioral or social communication therapies.
- The caps imposed on treatment under the neurodevelopmental therapies mandate make effective duration of treatment unattainable by most Washingtonians with Autism. Children exceed their yearly benefit routinely and they are, in effect, uninsured for the rest of the year. In many cases, employer packages offer no neurodevelopmental therapies at all.
- Treatment is considered habilitative vs. rehabilitative and therefore is denied.
- Well-researched and well-established effective treatments for core symptoms of autism are only covered by two major employers, Microsoft (through Premera) and Military (through Tricare), these treatments are also not available through any other state agencies (DSHS, Mental Health agency).
- Medical treatment for autism is erroneously thought of as being available in schools and therefore not the responsibility of insurers.

Additionally, substantial evidence in the scientific and medical literature that was included in the submissions documents demonstrate that early detection and

intervention are critical to the ultimate functioning level of people with ASD, underscoring the importance of the benefit's focus on providing care for children under age 21.⁴

There is broad consensus across the medical and other fields that treat children with ASD (e.g., pediatrics, psychiatry, neurology and the allied fields of psychology, speech therapy, occupational therapy and physical therapy) that the ***best and most efficacious treatment of autism requires early recognition and diagnosis, as well as early intensive treatment while the brain has the maximum potential to recover and/or compensate for the underlying pathophysiologic processes.***

Intensive remediation through repeated appropriate behaviors in affected brain processes (communication, social responsiveness, sensory processing), which is analogous to physical therapy for victims of stroke or nerve damage, is very widely accepted as a critical element in the treatment of autism. The submitted evidence supporting this point is too numerous to list in their entirety but include the National Institute of Child Health and Human Development Autism Overview:

“Research shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. . . . Because a young child’s brain is still forming, early intervention gives children the best start possible and best chance of developing their full potential. Even so . . . it’s never too late to benefit from treatment. **People of all ages with ASDs at all levels of ability generally respond positively to well designed interventions.**”⁵

However in Washington state intensive remediation for autism is not available to the general public. Aside from two employers, Microsoft and the military, intensive remediation for autism is **not** available through employer health benefits, state health agencies, DSHS, DDD, or mental health agencies.

(iii) If the benefit is not generally available, to what extent has its unavailability resulted in persons not receiving needed services?

Peele et al⁵ analyzed data from 128 behavioral health plans that were in effect in 1996 and 1998 to determine the exclusions and limitation in coverage. They found that a

⁴ There are too many pieces of submitted evidence attesting to this to list all of them, but examples include Bryson SE, Rogers SJ, Frombonne E, 2003. Autism spectrum disorders: early detection, intervention, education, and psychopharmacological intervention. Canadian Journal of Psychiatry, 48: 506-516; Rogers, SJ, 1998. Empirically supported comprehensive treatments for young children with autism. Journal of Clinical Child Psychology 27:168-179; New York State Department of Health, Clinical Practice Guideline, Report of the Recommendations Autism/Pervasive Developmental Disorders 1999; publication no 4215 and Clinical Practice Guideline: The Guideline Technical Report, 1999.

⁵ Peele PB, Lave JR, Kelleher KJ. Exclusions and limitations in children’s behavioral health care coverage. Psychiatric Services. 2002; 53:591-594.

significant proportion of plans had benefit exclusions and limitations for ASD. The authors concluded that affordability of treatment (health plan coverage increases affordability for families) is an important determinant of access. Exclusions and high co-payments were also important determinants of access. Because of benefit limitations, the authors report that parity legislation did not often meet the health care requirements of children with behavioral health needs. Furthermore if children exceeded their yearly benefit they would be, in effect, uninsured for the rest of the year.

Similar to the above study, the high cost of treatment has forced Washingtonians with autism to go without prescribed medically necessary treatments and needed services. This is widely reported by families from all across Washington State and documented by the Caring for Washingtonians Autism Task Force final report to the Governor and Legislature⁵.

(iv) If the benefit is not generally available, to what extent has its unavailability resulted in unreasonable financial hardship?

In the absence of coverage, out-of-pocket expenses for services can cost upwards of \$50,000 per year. In the process of trying to attain medical treatments and therapies, many risk their homes and the educations of their unaffected children – essentially mortgaging their entire futures.

The Caring for Washingtonians with Autism Task Force Final Report to the Governor and Legislature Priority Recommendations and Implementation Plans⁶ issued by the Department of Health in December 2007 contains extensive commentary on the inadequacies in the diagnosis, treatment, and support services for children in Washington with ASD and the impact of these inadequacies on families. The Task Force was comprised of family members of people living with autism, service providers, educators, administrators and researchers. It was charged with developing a plan for a new system of organization, coordination, and delivery of services to people with autism in Washington. Among the inadequacies identified were limitations in the state agencies for identifying and treating autism and the shortage of qualified providers to diagnose and treat ASD due in part to the lack of insurance coverage for necessary services.

Sharpe & Baker (2007) have reported in the Journal of Family and Economic Issues on a study of financial issues associated with having a child with autism.⁷ Between July 2003 and May 2004, the authors surveyed a convenience sample of 333 parents and primary caregivers living in the Midwest who had a child with autism under age 19.

⁶ The Caring for Washingtonians with Autism Task Force Final Report to the Governor and Legislature Priority Recommendations and Implementation Plans December 2007
http://www.doh.wa.gov/cfh/mch/Autism/documents/2007_Report/ATFRptFinal1207.pdf

⁷ Sharpe DL & Baker DL (2007). Financial issues associated with having a child with autism. Journal of Family and Economic Issues 28:247-264.

They asked questions about autism-related expenses, receipt of publicly funded services, financial problems, and employment difficulties. They analyzed responses to the following (yes/no) question: “During the past twelve months, has your family had financial problems because of your child’s autism or related conditions?”

Two main characteristics distinguished the families who reported experiencing financial problems:

(1) they utilized medical interventions and had un-reimbursed out-of-pocket expenditures for medical doctor or therapy or services (by 121%, 264%, and 289%, respectively) and

(2) those with incomes under \$40,000 were more likely to have financial problems than those with higher incomes. The authors also noted *“Many survey respondents forfeited financial security and even experienced bankruptcy to provide needed therapy for a child with autism”* (Sharpe & Baker, 2004, p. 247, 259).

(v) What is the level of public demand for the benefit?

To gauge the demand for the proposed benefit from the public, one would need to assess the amount of unmet need and the amount of family out-of-pocket costs that would be covered by the benefit. Washingtonians with Autism and their families, treating physicians, therapy providers, Medical centers, hospitals and clinics are all affected adversely by the lack of benefit.

The evidence submitted on lack of health care coverage, health care costs and expenditures, health services use, and the burden of autism (financial and humanistic), have led all the above parties to demand for this benefit.

The submitted evidence, reviewed in detail below, does present evidence that caring for children and young adults who have ASD are expensive, and that the increased costs of care, relative to children and young adults without ASD, are driven by direct medical costs (physician visits, therapies, non-pharmacologic treatments, psychotropic medications, psychiatric hospitalizations), and indirect costs (lost productivity/income of parents and caregivers)

Burden of Autism

A number of articles are submitted as evidence about the burden of autism. Järbrink, and Knapp (2001)⁸ and Ganz (2007)⁹ present data on the financial burdens of autism and Sánchez-Valle et al (2008)¹⁰ provide evidence about the humanistic burden of autism. Järbrink and Knapp⁸ present an often-cited cost of illness (COI) model from the

⁸ Järbrink K, Knapp M. The economic impact of autism in Britain. *Autism*. 2001;5:7-22.

UK perspective that is similar in methodological approach to the one published by Ganz (2007).⁹ Costs for hospital services, other health and social services, living support, voluntary support, special education, medications, sheltered work (supported employment), day activities, lost productivity, family members' time costs, and family expenses were enumerated, costed, and combined to estimate the cost of autism.

Informal care costs were excluded due to uncertainty and lack of information and direct costs did not include costs associated with investigational or experimental treatments or criminal justice. Although, in general, the cost model itself has face validity and is widely cited.

More recently Ganz⁹ estimated the lifetime costs of autism from a societal perspective for the United States. Using age- and sex-specific data on direct medical, direct non-medical, and indirect costs, Ganz estimated an average per capita discounted lifetime cost of \$3.2 million per person. This model is similar in construction to the model presented by Järbrink and Knapp.⁸ Ganz, however, provides the costs of each component of care in 5-year age categories which allows the reader to understand which costs are more relevant at different ages. The relative importance of different costs at different ages provides information on the source of payments.

According to Ganz, the total discounted lifetime costs of behavioral therapies (ending at age 21) are \$206,333, which is the largest component of direct medical costs. These behavioral therapies were estimated to cost more than the total lifetime costs of special education per child (\$150,483).

This article has been cited numerous times by a number of state governments to support extended services and mandated health insurance expansions for children and adults with autism (Missouri Department of Mental Health, the Alaska Governor's Council on Disabilities and Special Education, Caring for Washington Individuals with Autism Task Force, Arizona Autism Insurance Council, and the Nevada Department of Health and Human Services Autism Summit report).

In addition to economic burden of autism, there is a considerable humanistic burden of autism. Sánchez-Valle, et al¹⁰ present an estimate of the disability adjusted life years (DALY), which is a population-level measure of the burden of illness.

(vi) What is the level of interest of collective bargaining agents in negotiating privately for inclusion of this benefit in group contracts?

All who are affected adversely by lack of coverage of Autism related medical care and therapies are highly motivated to have this benefit included in group contracts. We do

⁹ Ganz ML. The lifetime distribution of the incremental societal costs of autism. Archives of Pediatrics and Adolescent Medicine. 2007;161:343-349.

¹⁰ Sánchez-Valle E. Posada M, Villaverde-Hueso A, et al. Estimating the burden of disease for autism spectrum disorders in Spain in 2003. Journal of Autism and Developmental Disorders. 2008;38:288-296.

not have sufficient information at this time regarding interest in collective bargaining agents.

(b) The financial impact:

(i) To what extent will the benefit increase or decrease the cost of treatment or service?

There have been parity benefits for autism across the nation which have provided data on claims impact. According to "Health Watch, For Professional Recognition of the Health Actuary", Issue 54, January 2007, page 21, Table 1: Marginal costs of mandated benefits for Autism were 0.0023% increase in total cost.

According to Council for Affordable Health Insurance (CAHI) Health Insurance Mandates in the States 2008 report, a state-by-state breakdown of health insurance mandates and their costs, lists estimated cost of autism at an unspecified percentage of <1%.

(ii) To what extent will the coverage increase the appropriate use of the benefit?

Individuals with Autism all throughout Washington state will have access to medically necessary treatments prescribed by their treating physicians.

Three different research groups found that autism specific services are used by about 1/500 children (range 1/476 to 1/521).¹¹ Johnson and Hastings¹² found that financial limitations are a significant barrier to obtaining early intensive intervention. Some of these barriers (e.g., limited resources to cover transportation to appointments) might still be in effect even if the insurance parity were in place. However, it seems likely that with one barrier (cost of service which is probably the most expensive) eliminated, use would increase.

(iii) To what extent will the benefit be a substitute for a more expensive benefit?

In the absence of benefits and resources for effective treatment, Washington children with

¹¹ Leslie DL, Martin A, (2007). Health care expenditures associated with autism spectrum disorders. Archives of Pediatrics and Adolescent Medicine 161:350-355.; Litak GS, Sutart T, Auinger P, (2006). Health care utilization and expenditures for children with autism: data from U.S. national samples. Journal of Autism and Developmental Disorders. 36:971-879; Mandell DS, Cao J, Ittenbach R, Pinto-Martin J (2006). Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. Journal of Autism and Developmental Disorders 36: 475-485.

¹² Johnson E, Hasting RP, 2002. Facilitating factors and barriers to the implementation of intensive homebased behavioral intervention for young children with autism. Child Care and Health Development. 28:123-129.

autism are placed in foster care, which is seldom available given their extensive health care needs, residential homes and institutions. Fircrest, a Washington residential institution has had children referred as young as 6 years old. Here in WA, the cost to taxpayers when a person becomes a ward of the state is \$4.3 million - \$7.2 million over the course of their lifetime.

In Washington state treatment resources for school aged children with autism are only available in crisis situations in form out of home residential placement and institutional care.

Community ICF-MR's are private facilities in the community (only 5 or 6 in the state)
SOLA's are state operated living arrangements (state employees working at state run residential homes)

RHC- residential habilitation Center--"institution", we have 5, Fircrest is one of them.

On average, what is the cost of a staffed residential placement for a child?

Answer: \$298.15 = \$108,824.75 per yr

What are the costs of the small community ICF/MRs?

Answer: \$210 per day. FY08 to date. = \$76,650 per yr

What are the Cost of SOLAs?

Answer: \$348 per day. FY08 to date + estimate for non-ADSA costs (depreciation and indirect costs) = 127,020 per yr

What is the current average annual cost of a person in RHCs?

Answer: \$527 per day. FY08 to date + estimate for non-ADSA costs (depreciation and indirect costs)= \$192,355 per yr (this is an average of all the institutions, Fircrest being the most expensive- cost for children has been higher, see below.)

Annual Claim Rates for Nursing Facilities and ICF-MRs	Nursing Facilities	ICF-MRs	Combined	
Fircrest NF				
Fircrest ICF-MR		\$232,300		
Fircrest combined			\$215,900	
Frances Haddon Morgan ICF-MR		\$195,600		
Statewide NF				
Statewide ICF-MR				
Statewide combined		\$194,000	\$191,200	

Data: DDD3-26-2008; Chart: Margaret-Lee Thompson, King Co. Parent Coalition for D.D. 5-13-08

In a 2006 article, David Mandell cites 10 years of research articles that suggest substantial improvements in functioning among children with ASD after behavioral rather than pharmacologic interventions.¹³ In one cited study, 47% of the children in the behavioral treatment conditions achieved “normal intellectual and educational functioning” as compared to 2% of those who received standard medical and educational benefits only.

Higher levels of functioning are associated with lower health care costs. Children with Autism who are lower functioning are more likely to use higher amounts of health care services for outpatient visits, medication and inpatient stays.

In another 2006 article, Liptak et al. report on data from three (3) national health surveys conducted in 1999 and 2000 that reveal health care utilization and expenditures for children with Autism.

Findings from this study indicate that children with Autism, who most often lack coverage for effective behavioral therapies, use substantially more outpatient visits and use physician time longer during each visit than.¹⁴

Lack of the benefit clearly leads to delays in diagnosis and in implementing recommended treatments. Such delays are likely to directly impact families and educators of affected children. In addition they are likely to indirectly effect public schools and the Washington Medicaid system, as they are required to provide specialized education and more intense psychiatric treatment to children who have more severe autism-related impairments because they failed to receive early intervention.

The resources expended by these public agencies to meet the needs of children with autism who do not receive the benefit will either be taken from other programs in the agencies that serve other Washingtonians or will need additional tax support. Lack of the benefit also results in un-reimbursed medical expenses for many families who feel compelled to provide whatever treatment they can and but are not accessing those services through Medicaid. Several citizens and one survey reported that it is frequent for one parent to withdraw from the work force in order to provide such services directly or advocate for them.

Loss of these parents from the work force reduces the tax base and may increase the likelihood of family bankruptcy. In the case of single parent families, the requirement for intense parent involvement to the exclusion of paid work, may lead to need for welfare assistance. Utilizing all one's savings, retirement and college funds also increases the likelihood of financial catastrophe and dependence on welfare agencies for both the parents and for the affected child with autism once s/he becomes an adult.

¹³ Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

¹⁴ Liptak GS, Stuart T, Auinger P. Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*. 2006; 36:871-879.

Finally, lack of the benefit and failure to provide sufficiently intense treatment (ABA) through Medicaid appears to reduce the number of individuals with autism who are able to achieve higher levels of functioning. Put another way, lack of the benefit and associated failure to provide sufficiently intense treatment is likely to increase the number of individuals who are dependent upon others for housing, supervision and vocational support as adults. Such services must be provided by the state, which will require funds be taken from other programs or increased taxes. It also seems likely that the healthcare needs of more severely ill youth and adults with autism will be greater than the healthcare needs of youth and adults with milder symptoms.

Detailed discussion of each of these social impacts follows. Diagnostic and treatment delays as well as inadequate treatment resulting in more severe illness clearly increase stress on parents. One study found that the mean depression score among parents of children with autism was twice that found in community surveys and that 45% of the sample (68 parents) met the cut off for a major depression.¹⁵ Parental depression is well established to adversely affect the mental health and development of typically developing children who may be siblings of the autistic child.

Further more severe autistic symptomatology is linked to higher levels of depression and stress, which – in contrast to moderate or mild symptomatology – was not sensitive to support provided by others in the community. Several studies (initial reports not provided) have noted that autism seems to affect the family (parents and siblings) to a greater extent than other developmental disorders.¹⁶

Autism Society of America as well as the National Autism Association have cited a divorce rate of 80% - 85% among parents of children with autism. With such a rate in divorce, there is social impact on higher costs of monitoring child support payments and greater likelihood that children will live in poverty if living in single parent families. Further, the rate of psychiatric hospitalization for children with autism in single parent families was greatly increased (odds ratio 2.54).¹⁷

In 2004, Mandell reported a study of publicly and privately insured Pennsylvania children with ASD, examining their rates of inpatient psychiatric hospital use. The chief

¹⁵ Benson, PR (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: the mediating role of stress proliferation. *Journal of Autism and Developmental Disabilities*. 36:685-695.

¹⁶Bouma; R & Schweitzer, R.; 1990. the impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *Journal of Clinical Psychology* 46:722-730.; Moes,D.; 1995. Parent education and parent stress. In RL Koegel & LK Koegel (Eds.) *Teaching children with autism* (pp.79-94) Baltimore: PH Brookes Publishing.; Rodrigue,JR; Morgan,SB; Geffken,.; 1990. Families of autistic children: psychosocial functioning of mothers. *Journal of Clinical Child Psychology* 19: 371-379.

¹⁷ Mandell,DS (2007). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, Nov 2007, epub ahead of print.

finding of the study is that there was significant separation in rates of hospitalization between children who had earlier diagnosis and received Early Intervention and those who did not; the late diagnosed group who did not receive early behavioral interventions had significantly higher rates of self-injury and aggression.¹⁸

In this Pennsylvania study, Mandell found significant variation in results across the Counties, which he interpreted to reveal variation in health system factors that drove the differences, rather than differences inherent to the population of the Commonwealth's children with ASD. Mandell separately studied use of psychotropic medications nationally among children with ASD and found that as many as 56% are prescribed one or more psychotropic drugs and as many as 20% of these children are prescribed three or more drugs concurrently.¹⁹

(iv) To what extent will the benefit increase or decrease the administrative expenses of health carriers and the premium and administrative expenses of policyholders?

Analyses based on claims databases have been published by Health Watch "For Professional Recognition of the Health Actuary", Issue 54, January 2007, page 21, Table1, Marginal Costs of Mandated Benefits report 0.0023% increase in total expenses.

Council for Affordable Health Insurance (CAHI) Health Insurance Mandates in the States 2008, a state-by-state breakdown of health insurance mandates and their costs, reports estimated cost of 11 states with mandates autism benefits to be <1%.

(v) What will be the impact of this benefit on the total cost of health care services and on premiums for health coverage?

Coverage has been in effect in 23 other states and the claims expenses have been documented both in Health Watch and CAHI. These marginal expenses are reported to be 0.0023 % to an unspecified number of <1%. There are also 8 states that have passed Autism Insurance Parity in 2007-2008 legislative sessions. Cost analysis reports from PA and AZ has been submitted.

(vi) What will be the impact of this benefit on costs for state-purchased health care?

The impact should be negligible, comparable to the claims data that have been

¹⁸ Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).

¹⁹ Mandell DS, Morales KH, Marcus SC, Stahmer AC, Doshi J, Polsky DE. Psychotropic medication use among Medicaid-enrolled children with autism spectrum disorders. *Pediatrics*. 2008; 121:e441-e448.

documented above. Microsoft Corporation is a WA state company. They have had autism parity in place voluntarily for several years. Their claims impact on administrative costs can provide Washington state insight on whether there is any different than those published by insurance industry sources cited above.

(vii) What will be the impact of this benefit on affordability and access to coverage?

This benefit would make treatments attainable and affordable to families who currently have no access to medically necessary treatments, due to the prohibitive costs. This would in turn support and increase provider capacity leading to much improved access to treatment. In the states where autism parity has been in existence, there has only been significant improvement in terms of affordability and access to coverage. An overview of states with existing autism insurance parity laws have been submitted.

(c) Evidence of health care service efficacy

There are over 700 published studies that document effectiveness of intensive behavioral therapies (Applied Behavior Analysis) for developing many important skills in people with ASD *of all ages* (e.g., Matson et al., 1996; New York State Department of Health, 1999; *Journal of Applied Behavior Analysis*):

- Learning to learn: looking, listening, imitating, following instructions, discriminating and matching stimuli, etc.
- Communication: verbal and nonverbal; comprehension and production; from simple vocalizations to complex conversations
- Social: simple reciprocal exchanges, playing with peers, sharing, expressing emotions, empathizing, dramatic play, etc.
- Self-care: hygiene, personal safety, community living, etc.
- Motor and leisure

And much more, for an array of these published studies, please refer to the documents submitted in support of the efficacy of treatments for Autism.

Numerous published reports have been submitted as proof of efficacy of treatments for autism. There are simply too many to list individually. These empirically validated, peer reviewed published reports are from national sources as well as Washington state sources. Please refer to submitted peer reviewed empirically validated articles on efficacy of treatment in individuals with autism of all ages. A few notable studies have been mentioned and interspersed below. These studies have compared efficacy of early intensive behavioral interventions (EIBI) versus intensive traditional eclectic models (Speech therapy, occupational therapy, TEACCH), as well as versus current models available through Washington state lead agencies.

(i) If a mandatory benefit of a specific service is sought, to what extent has there been conducted professionally accepted controlled trials demonstrating the health consequences of that service compared to no service or an alternative service?

The proposed benefit mandates that “treatment for autism spectrum disorders” shall include the following care prescribed, provided or ordered for an individual diagnosed with an autism spectrum disorder by a [licensed professional] if the care is determined to be medically necessary” (i.e., as defined by the bill: any care, treatment, intervention, service or item which is prescribed, provided or ordered by a licensed physician, licensed psychologist or certified registered nurse practitioner in accordance with accepted standards of practice and which will, or is reasonably expected to, do any of the following:

- i) prevent onset of . . . disability;
- ii) reduce or ameliorate the physical, mental or developmental effects of an illness . . . or disability;
- iii) assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account . . . those functional capacities that are appropriate of recipients of the same age,

Including:

- i) psychiatric care
- ii) psychological care
- iii) habilitative and rehabilitative care [which is defined to include applied behavioral analysis (ABA)];
- iv) therapeutic care [defined to mean services provided by licensed or certified speech therapists, occupational therapists or physical therapists];
- v) pharmacy care [defined to mean medications prescribed by a licensed physician or certified registered nurse practitioner and any health related services deemed medically necessary to determine the need or effectiveness of the medications]
- vi) any care, treatment, intervention, service or item for individuals with an autism spectrum disorder developed by a licensed physician or licensed psychologist pursuant to a comprehensive evaluation or reevaluation performed in a manner consistent with most recent clinical report or recommendations of the American Academy of Pediatrics which is based upon review of best practices of evidence-based research, to be medically necessary and which is published in the Revised Code of Washington (RCW).

Thus the only “*specific service*” specifically mentioned by the Autism Insurance Parity is applied behavioral analysis (ABA).

There is extensive professionally accepted evidence supporting the efficacy of ABA

compared to no or minimal therapies and to alternative therapies. The strongest evidence is provided by Eikeseth, Smith, Jahr and Eldevik (2002²⁰, 2007²¹). The Eikeseth et al., 2007 paper and Eikeseth et al., 2002 article, report on different phases of outcome in the same study.

In this study, 25 children with autism between the ages of 4 and 7 were assigned to receive a minimum of 20 hours/week of either ABA treatment or eclectic treatment by an independent state funded autism specialist. Treatment assignment was based upon availability of qualified supervisors with no regard to child characteristics or parent preference. Treatment assignments were made over a 3-year period so cohort effects are likely to be minimal. Each child was integrated into a different school with their own individual therapists, so there were not treatment center effects.

The ABA therapy used the manual and videotapes developed by Lovaas but did not include any aversive contingencies. The treatment focused on very simple tasks such as responding to an adult and gradually progressed to more complex tasks such as conversing and making friends. Initially all treatment was individual, discrete trial format but later focused on generalization to the classroom setting. The therapists did not have prior training but received 10 hours of supervision weekly from supervisors who had a minimum of 1,500 hours of experience implementing ABA treatment and met recommended ABA qualification criteria²² and 1-2 hours weekly with the team directors, who were psychologists, each of whom had 10 years experience or more implementing the UCLA treatment. In addition weekly 2-hour meetings were held with child, primary caretaker, therapists, supervisors, and director. Parental participation was also central with parents working along side therapists 4 hours per week during the first 3 months and then continuing the intervention in the home setting.

The comparison eclectic treatment was designed to meet best practices as outlined by Dawson & Oesterling.²³ This treatment incorporated elements from Project TEACCH, sensory motor therapies, and ABA. The specific interventions were individually selected for the child based on recommendations from a multidisciplinary team. The interventions were implemented on a 1 to 1 basis with the same therapist serving as an aid during classroom activities. The therapists received weekly, 2-hour consultations from the supervisors and same directors as provided leadership for the ABA intervention group.

²⁰ Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-yearold children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68.

²¹ Eikeseth S, Smith T, Jahr E, Eldevik S, (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. A comparison controlled study. *Behavior Modification* 31:264-278.

²² Smith T, Donahoe PA, Davis BJ, (2000). The UCLA treatment model. In S.L. Harris and J.S. Handelman (Eds.), *Preschool education programs for children with autism* (2nd edition, pp29-48). Austin, TX: Pro-Ed.

²³ Dawson G, Osterling J, (1997). Early intervention in autism. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 307-326). Baltimore: Paul H. Brookes.

Outcome assessments were performed by a blinded psychologist or psychological examiner with a master's degree in special education, both of whom had extensive experience with children with autism. The outcomes included standardized tests of general cognitive functioning (IQ), visual-spatial skills, language and adaptive behaviors.

Treatment hours were 28 in the ABA group and 29 in the eclectic comparison group. Therapist education was similar for both groups. Mean intake IQ was 61.92 in the ABA group and 65.00 in the eclectic comparison group. On measures of language and adaptive behavior a similar pattern was observed with the ABA group showing numerically lower baseline values (including IQ 3.3 points lower, total language 8.2 points lower and adaptive behavior 4.2 points lower) for 10 of the 11 measures of interest.

After 1 year of treatment, the ABA group improved mean IQ by 17 points (SD = 11), total language by 27 points (SD = 20), and adaptive behavior by 11 points (SD = 15). In contrast, the eclectic comparison group improved IQ by only 4 points (SD = 8) points, total language by 1 point (SD = 17), and adaptive behavior by < 1 (8) point. All of these between group differences in change from baseline scores were statistically significant at the (one-sided) $p < 0.01$ to 0.05 level.

At end of the follow-up period the ABA group's scores were consistently higher than the eclectic group.

The two treatments were then continued for nearly two more years. Three years after entering the study, the children were reassessed by blinded evaluators. The ABA group improved IQ from baseline by a total of 25 points, Vineland daily living skills by 9 points and Vineland communication by 20 points. The eclectic comparison group improved IQ by a total of 7 points, but showed decreases of 6 to 12 points on the Vineland subscales. In addition the ABA group showed fewer social problems, less aggression and fewer Vineland maladaptive behaviors than the eclectic group. Fifty-four percent (54%) of the ABA group and only 17% of the eclectic group scored within the normal range of IQ. Interestingly, IQ changed most dramatically early in ABA treatment and daily living skills and adaptive and social behaviors as reflected by Vineland scores changed most later in ABA treatment. A similar pattern was not observed in the eclectic comparison group.

In addition to this well-controlled study, there are a number of other studies comparing ABA to other treatments in a less rigorous way and in different treatment settings that also show fairly consistent evidence of benefit of ABA on cognitive functioning and ability to function in much more age-appropriate fashion. Three of these studies are discussed here.

A study by Howard et al. (2005)²⁴ compared 29 preschool children receiving ABA (25-40

²⁴ Howard JS, Sparkman CR, Cohen HG, Green G, Stanislaw H, (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26:359-383.

hours/week), 16 children receiving 30 hours/week of 1:1 or 1:2 eclectic intervention (combination of TEACCH, sensory integration and some ABA) and 16 children in a non-intensive 15 hour/week 1:6 group intervention (13 of whom also received speech therapy). The treatment each child received was determined by regional early intervention center but heavily considered parental preference.

Treatment in the ABA group was provided by college students under direct supervision of a master's level clinician with extensive ABA experience under the guidance of a

Board Certified Behavior Analyst (PhD in psychology or speech therapist). Children were assessed after 7-14 months of treatment by an independent contractor. Intervention groups differed significantly at baseline with respect to age of diagnosis, age at onset of treatment, age at follow-up testing, and parents' education.

Children in the ABA group showed a 11pt (SD 15) gain on a composite cognitive scale and a 21 (11) month gain in communication skills, compared to a one point (SD 12) decrease in the cognitive measure and a 8 (10) month gain in communication in the intensive eclectic program and a 3 point (14) decrease in the cognitive measure and 10 (9) month gain in communication in the low intensity program. The differences with respect to each of these follow-up measures between the ABA group and the two comparison groups combined are statistically significant at the $p < 0.05$ level. In addition, more than half of the children in the ABA group showed learning rates above normal after the intervention whereas very few in the other two groups did.

A randomized controlled trial conducted by Smith, Groen and Wynn²⁵ that provides nearly as strong evidence as the Eikeseth et al. study. In the Smith, Groen and Wynn study, 28 children with ASDs, mean age 3 years, were randomly assigned to receive intensive ABA which included a parent component for 5 hours/week for the first 3 months or parent training in ABA methods for five hours/week for 3 to nine months. In both condition's Lovaas's 1981 manual was utilized but did not include the use of negative consequences (aversives) except for a very brief period in the initiation of the study. The mean therapy received by the ABA group was 24.5 hours/week during the first year, with gradually reducing hours in the second and third years. ABA treatment was administered by college students who were supervised by the authors who had a combined total of 10 years experience under Lovaas's supervision. Further these student therapists were required to pass written tests on the treatment methodology and a standard behavioral test of them administering the intervention. Only therapists with a minimum of 1,500 hours of experience were allowed to become supervisors. The control group did not receive further intervention from the study once parent training was completed.

Participants were assessed at baseline and when they were 7-8 years old (2-3 years following completion of the intervention). Assessments were done by a clinician who was blinded to the treatment each participant had received. At baseline, 82% of the

²⁵ Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.

children were nonverbal and none achieved a basal score on the Stanford-Binet IQ test; mean baseline IQ in both groups was 51. At follow-up, children in the ABA group had a mean IQ of 66 (increase of 16 points) while those in the parent-training group had a mean IQ of 50 (1 point decline).

Total language scores increased by 58 points in the ABA group (29 to 87) and by 31 points in the parent group (30 to 61). Several children in the ABA group showed ceiling effects that may have reduced the apparent differences between the two groups. Six of the 15 children in the ABA group (40%) were in regular education (4 without an aid) whereas only 1 of the 13 in the parent group (8%) was in regular education and had an aid. All of these changes were statistically significant. The authors speculate that the lower intensity of this program may account for the less dramatic response observed compared to Lovaas's initial study.

A similar study was conducted by Cohen and colleagues.²⁶ They studied 21 children younger than 3 years of age who received 35-40 hours/week of ABA therapy for three years and 21 age and IQ matched children in a variety of community early intervention services with fewer than 9 hours/week ABA. Treatment assignment was not randomized but rather based on parent preference. Outcome assessments were conducted by independent examiners who appear blinded to the treatment each child received. At baseline, the ABA group had numerically higher IQ (61.6 vs. 59.4), nearly identical language skills and Vineland adaptive behavior scores. The mean IQ increased by 25 points in the ABA group and 14 points in the control group, language composite increased by 20 points in the ABA group and 9 points in the comparison group, and Vineland adaptive behavior composite increased by 9 points in the ABA group but declined by 4 points in the comparison group. Both of these comparisons were statistically significant.

Findings from these studies consistently show that focused ABA programs can provide outcome advantages over equally intense eclectic programs even when those programs incorporate ABA techniques.

(ii) If a mandated benefit of a category of health care provider is sought, to what extent has there been conducted professionally accepted controlled trials demonstrating the health consequences achieved by the mandated benefit of this category of health care provider?

At the clinical decision-making level, Autism Insurance Parity does not extend coverage to "an additional class of practitioners" who are not already planning and overseeing the implementation of treatment or other services to children with ASD. Specifically, Autism Insurance Parity amends Washington's Insurance Laws to indicate that with respect to autism spectrum disorders:

²⁶Cohen H, Amerine-Dickens M, Smith T, (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27:S145-S155.

(F) 9. “Medically necessary” means any care, treatment, intervention, service, or item that is prescribed, provided, or ordered by a licensed physician or a licensed psychologist that will, or is reasonably expected to, do any of the following:

- a. Prevent the onset of an illness, condition, injury, or disability;
- b. Reduce or ameliorate the physical, mental, or developmental effects of an illness, condition, injury, or disability; or
- c. Assist to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the individual and the functional capacities that are appropriate for individuals of the same age.

The licensed and/or certified professionals who are empowered by Autism Insurance Parity to plan and oversee ASD treatment are the traditional groups who authorize and provide such treatment, and as such do not constitute an “additional class.”

One potential issue with respect to “new” practitioners, however, may be with Board Certified Behavior Analysts, Board Certified Associate Behavior Analysts and Therapy assistant non-clinical personnel who directly design, train, oversee, implement and provide applied behavioral analysis (ABA) treatment.

Currently BCBA’s, BCABA’s and therapy assistants are covered by Microsoft (Premera) and Military (TriCare Echo) insurance.

Several peer-reviewed, controlled studies documenting the efficacy of ABA were included among the submitted evidence. The three studies described in detail in section (c) (i), all provide detailed descriptions of the content and procedures of ABA treatment and the training required for the therapists working most directly with the children²⁷. Additionally, parental participation was a critical element of the treatment, and parents were also trained by therapists in implementing the one-to-one elements of the treatment.

²⁷ Eikeseth S, Smith T, Jahr E, Eldevik S, (2002). Intensive behavioral treatment at school for 4- to 7-yearold children with autism. A 1-year comparison controlled study. *Behavior Modification* 26:49-68. ; Eikeseth S, Smith T, Jahr E, Eldevik S, (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. A comparison controlled study. *Behavior Modification* 31:264-278.; Smith T, Groen AD, Wynn JW, (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation* 105:269-285.; Cohen H, Amerine-Dickens M, Smith T, (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27:S145-S155.

(iii) To what extent will the mandated benefit enhance the general health status of the state residents?

Autism Insurance Parity will lead to improved access to evidence based behavioral therapies, including Applied Behavioral Analysis. This will improve independent functioning and quality of life for those children and youth with ASD who will have access to medically necessary treatments not currently attainable for them.

In 2004, Mandell reported a study of publicly and privately insured Pennsylvania children with ASD, examining their rates of inpatient psychiatric hospital use. The chief finding of the study is that there was significant separation in rates of hospitalization between children who had earlier diagnosis and received Early Intervention and those who did not; the late diagnosed group who did not receive early behavioral interventions had significantly higher rates of self-injury and aggression.

In a 2006 article, David Mandell cites 10 years of research articles that suggest substantial improvements in functioning among children with ASD after behavioral rather than pharmacological and psychological interventions. In one cited study, 47% of the children in the behavioral treatment conditions achieved “normal intellectual and educational functioning” as compared to 2% of those who received standard medical and educational benefits only.²⁸

In autism, enhanced health and diminished effects of the disorder is improved functioning, improved engagement, socialization and communication, and reduced maladaptive behaviors. Autism Insurance Parity will enhance the general health status of the Washingtonians with autism significantly; furthermore it will alleviate much of the deterioration of health and emotional strain on families and caregivers of individuals with autism.

²⁸ Mandell D, Cao J, Ittenbach R, Pinto-Martin J. Medicaid expenditures for children with autistic spectrum disorders: 1994-1999. *Journal of Autism and Developmental Disorders* 2006; 36(4).